

**Notes for Discussion on Future Roles of SDS Focus:
Promoting Research as Vital
to the Development of Disability Studies**

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I would like us to explore the ways that SDS can advance research activities in order to: provide a scientific base for 'Disability Studies'; and to assure that people with disabilities are included and disability status specified in research on all, or at least most, topics, not only when disability-related content is explicit.

To organize discussion, I suggest we consider: (I) Issues and barriers as well as supports that arise in promoting research within SDS, and (II) Specific activities and structures that are appropriate for SDS, including costs (resources) and benefits to SDS.

I. Barriers to, and supports for, supporting SDS' role in promoting research

A. Barrier: Resistance to (traditional) research by some people with disabilities, especially some IL (Independent Living movement) activist leaders. The topic has several subheadings; see unpublished paper by Simi Litvak and me, prepared for NIDRR (1996). Examples of issues:

Distrust of researchers by people with disabilities based on history of studies that violated peoples' rights; emphasis on quantitative methods that underrate experiential insights. On the other hand, devaluing expertise that doesn't include personal experience with disability.

Objections to "basic" research vs. "applied" research, insofar as IL philosophy calls for research that involves people with disabilities to demonstrate benefits for participants.

Appropriate role for medical rehabilitation research, given the rejection of 'the medical model' for most of what Disability Studies is concerned with.

B. Barrier: SDS members who are researchers compete for scarce research resources; are geographically and organizationally dispersed; can devote only small time inputs and do so on volunteer basis; represent diverse disciplines and research approaches, the latter sometimes posed as antagonistic, e.g. qualitative versus quantitative.

C. Supports: Many SDS members are researchers, some with influence over resources. Most points under I.B. that reflect diversity in research settings and approaches, can be turned from barriers into supports for the kind of roles SDS might take, but this requires structured safeguards against biases from dominance of one type of setting or perspective.

II. Activities and Structures to Promote Research (Note: By listing all of the following, I don't mean to imply I favor all of them, but feel they all merit consideration.)

A. Annual meetings could provide structured opportunities to pilot test new data collection techniques or questionnaire wordings, within regular meeting time or as an add-on;

B. SDS could provide a 'Seal of Approval' (need a better term; it should function like the symbol on websites that shows they meet accessibility criteria), or some review procedure without providing a seal, that indicates that a research project is assuring full inclusion of people with disabilities. The elements of a project that should be separately assessed are: sampling frame definition - conceptual and operational; data collection techniques; questionnaire wording; and interviewer training (if interviewers are used). The following apply but should be treated separately, because they occur after data collection: data analysis, reporting of nonresponse, and dissemination techniques.

C. SDS could provide a database and clearinghouse on accessibility techniques that have been used in research, with info on where technologies are available, and their relative strengths and weaknesses (including dollar and time costs; benefits for quality and quantity of responses; benefits for nondisabled participants) for use in specified research applications. A stronger aspect of this function would be to sponsor one or more methodology laboratories to work on research accessibility issues.

D. SDS could maintain rosters of members qualified to serve as peer reviewers for research funders or publishers of papers or books (generally unpaid except for expenses) or as paid consultants. The Directory currently serves this function I suspect, but if formalized, the database should contain addi-

tional information and should be accessible through varied keywords to represent types of interests and expertise.

E. SDS could help other professional associations review their codes and other standards regarding research with respect to inclusion of people with disabilities; e.g. AAPOR's (the American Association for Public Opinion Research) recent standards on reporting nonresponse.

F. SDS could promote (lobby for) greater federal funding for disability research, especially at NIDRR but throughout federal research agencies. As a related matter, SDS could stimulate and/or advise private foundations in providing research dollars.

G. SDS could run a formalized job exchange for researchers through its publications and meetings. (If undertaken, this would not be limited to research positions, should include teaching, consulting, etc.)

H. SDS could expand its role as a publisher of research, i.e. turn DSQ into a peer-reviewed journal, add a journal for peer-reviewed research, and/or publish research monographs.

I. SDS could help researchers recruit (a) collaborators to fulfill 'Participatory Action Research' objectives, and/or (b) subjects for research needing people with specific disability experience.

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